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It isn't pain pure and simple: Experiences of pain and discomfort in primary Sjögren's syndrome: A qualitative focus group study

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Abstract

Background: Pain is a major determinant of poor quality of life in primary Sjögren's syndrome (PSS) and a priority symptom for United Kingdom Primary Sjögren's Syndrome Registry (UKPSSR) patients. Although neuropathic and chronic pain phenotypes have previously been identified, little is really known about this symptom in PSS. In order to further explore the concept of pain in PSS further, focus groups were conducted with patients and their family members.

Methods: 10 UKPSSR patients in the north-east of England and 3 spouses of patients took part in 3 focus groups to explore their experiences of pain and other symptoms. They were asked to describe their pain and how they/their spouse managed it. Focus groups were audio-recorded and transcribed verbatim. Transcripts were analyzed using thematic analysis.

Results: Although pain is a feature of PSS, it was not experienced by all patient participants. For those who experienced pain, the levels varied and it was not present every day. The word 'pain' was not always regarded as an appropriate description of the experience and it should be used interchangeably with the word 'discomfort'. Pain and discomfort were regarded on a scale, from mild irritation through to excruciating pain. Pain and discomfort often followed a fatigue episode or excessive activity. Different experiences of pain and discomfort included; articular pain, aching muscles, headaches, peripheral paresthesia, noise intolerance, bowel discomfort, nausea, eye discomfort, cramp-like pain in the parotid glands and pain/discomfort relating to ill-fitting dentures and dental treatments. These experiences sometimes prevented engagement in social/leisure activities and could contribute to social isolation. Patients' believed that when others - including family and clinicians - demonstrate little understanding of these symptoms, it had a negative impact on their mood. Self-management strategies used by patients included regularly setting an achievable and enjoyable goal, use of TENs devices, and accessing alternative therapies e.g. Shiatsu and acupuncture.

Conclusion: Pain/discomfort in PSS is a heterogeneous concept. An empathic approach from the clinician towards patients' pain/discomfort may avoid further emotional distress for the patient. Experiences of pain and discomfort in PSS are unique and should be explored with the patient prior to planning appropriate targeted interventions.